

Perinatal Loss

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Note:

This guideline provides advice of a general nature. This statewide guideline has been prepared to promote and facilitate standardisation and consistency of practice, using a multidisciplinary approach. The guideline is based on a review of published evidence and expert opinion.

Information in this statewide guideline is current at the time of publication.

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Health practitioners in the South Australian public health sector are expected to review specific details of each patient and professionally assess the applicability of the relevant guideline to that clinical situation.

If for good clinical reasons, a decision is made to depart from the guideline, the responsible clinician must document in the patient's medical record, the decision made, by whom, and detailed reasons for the departure from the guideline.

This statewide guideline does not address all the elements of clinical practice and assumes that the individual clinicians are responsible for discussing care with consumers in an environment that is culturally appropriate and which enables respectful confidential discussion.

This includes:

- The use of interpreter services where necessary,
- Advising consumers of their choice and ensuring informed consent is obtained,
- Providing care within scope of practice, meeting all legislative requirements and maintaining standards of professional conduct, and
- Documenting all care in accordance with mandatory and local requirements

Explanation of the aboriginal artwork:

The Aboriginal artwork used symbolises the connection to country and the circle shape shows the strong relationships amongst families and the Aboriginal culture. The horse shoe shape design shown in front of the generic statement symbolises a woman and those enclosing a smaller horse shoe shape depicts a pregnant women. The smaller horse shoe shape in this instance represents the unborn child. The artwork shown before the specific statements within the document symbolises a footprint and demonstrates the need to move forward together in unison.

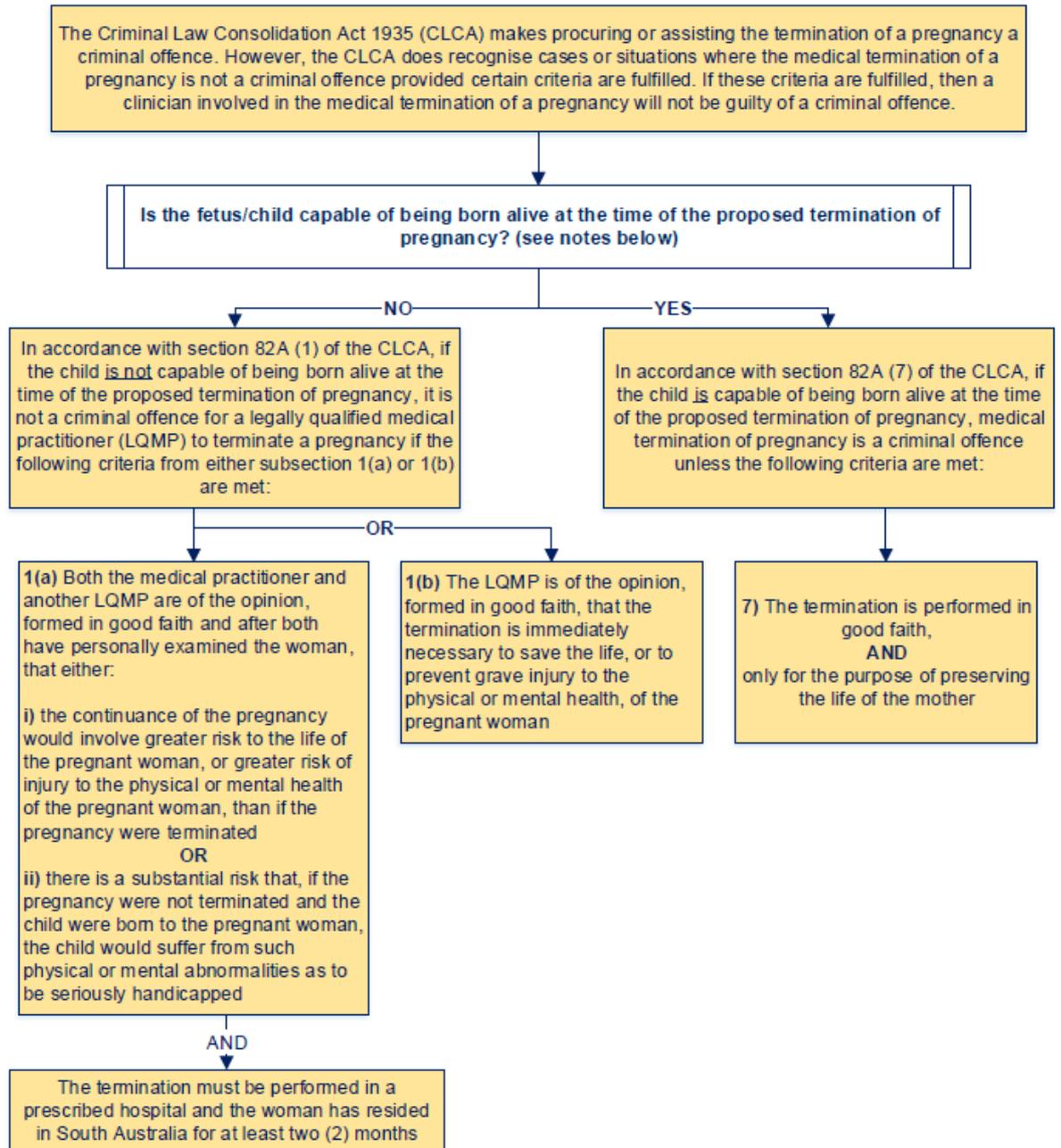


Australian Aboriginal Culture is the oldest living culture in the world yet Aboriginal people continue to experience the poorest health outcomes when compared to non-Aboriginal Australians. In South Australia, Aboriginal women are 2-5 times more likely to die in childbirth and their babies are 2-3 times more likely to be of low birth weight. The accumulative effects of stress, low socio economic status, exposure to violence, historical trauma, culturally unsafe and discriminatory health services and health systems are all major contributors to the disparities in Aboriginal maternal and birthing outcomes. Despite these unacceptable statistics the birth of an Aboriginal baby is a celebration of life and an important cultural event bringing family together in celebration, obligation and responsibility. The diversity between Aboriginal cultures, language and practices differ greatly and so it is imperative that perinatal services prepare to respectively manage Aboriginal protocol and provide a culturally positive health care experience for Aboriginal people to ensure the best maternal, neonatal and child health outcomes.

Purpose and Scope of Perinatal Practice Guideline (PPG)

The purpose of this guideline is to provide clinicians with information to support their care of women and their families experiencing perinatal loss in the second or third trimesters, either through fetal demise or termination of pregnancy. It includes legal, clinical and ethical considerations for women electing late stage termination of pregnancy or experiencing intrauterine fetal death. Documentation requirements, autopsy information and options for the management of the fetus/baby following birth are also included.

Flowchart: Medical Termination of Pregnancy – Guide for Clinicians Regarding Legality



Note 1: "Capable of being born alive"

A clinical assessment must be undertaken as to whether or not the fetus/child is capable of being born alive in each and every prospective termination case, and irrespective of the age of the fetus. The meaning of 'capable of being born alive' requires a consideration of fetal viability. This issue has not been tested in the Australian courts.

There is an evidentiary presumption in section 82A(8) of the CLCA¹ that 28 weeks gestation or more shall be the *prima facie* proof of a child capable of being born alive. However, that is a presumption only and may be rebutted. Based on local, national and international data, in the absence of a significant morbidity, the boundary of fetal viability currently lies between 23 and 25 weeks of gestation. However, currently 23⁺⁰ completed weeks of gestation (i.e. 23 weeks 0 days) is generally considered the point of fetal viability. Please note that this time period of 23⁺⁰ weeks is to be used as a guide only. The length of fetal gestation is only one of a number of factors that can be considered in assessing whether the fetus/child is capable of being born alive. It is necessary for clinicians to make their own evaluations based upon all available information.

Note 2:

In determining whether the continuation of a pregnancy would involve such risk to the physical or mental health of the woman, account must be taken of the woman's actual or reasonably foreseeable environment.

Note 3: "Prescribed hospital"

Listed in Schedule 3 CRIMINAL LAW CONSOLIDATION (Medical termination of pregnancy) REGULATIONS 2011².

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Summary of Practice Recommendations

Parental decisions about screening, diagnostic testing and continuation of pregnancy must be made on the basis of clear information about the nature of the fetal anomaly and risks of the available interventions.

In determining whether the fetus has the capacity to be born alive, consideration must be given to all clinical factors rather than gestation alone.

Following a decision to proceed with termination of pregnancy (TOP) in the second trimester, the TOP can be undertaken medically or surgically depending on gestation, women's preference and other clinical considerations.

Births following TOP are not registrable with Births, Deaths and Marriages, except in cases where the fetus exhibits overt signs of life at the time of birth.

Fetal demise known to be prior to 20 weeks gestation is not registrable (even if birth occurs after 20 weeks).

Intrauterine fetal death (stillbirth) from 20 weeks gestation is registrable.

Explanation and support for the woman and her family should begin immediately following confirmation of fetal death or decision for medical termination, including non-medical counselling.

Discuss the woman and her family's option to see, touch and hold the baby after birth, receive mementos), and take photographs. Offer appropriate support group information and brochures to the woman and her family.

Ask women if there are specific cultural practices that they need to observe/be aware of in order to provide culturally appropriate care as women have different values, perceptions and behaviours that differ not only across cultural backgrounds but also within their own culture.

In cases of stillbirth, autopsy and histopathological examination of the placenta is recommended in addition to following the *Investigation of Stillbirths: SA Protocol*.

Abbreviations

CLCA	Criminal Law Consolidation Act
IUFD	Intrauterine fetal death
LHN	Local Health Network
LQMP	Legally qualified medical practitioner
PPG	Perinatal Practice Guideline
SA	South Australia
SAFDA	Support after fetal diagnosis of abnormality
SANDS	Stillbirth and neonatal death support
TOP	Termination of pregnancy

Definitions

Cemetery	A place designated for the interment of human remains
Miscarriage	A fetus of less than 20 weeks that shows no signs of life following expulsion of the products of conception
Registrable	The birth of the fetus/baby meets the criteria to be registered with <i>Births, Deaths and Marriages</i> in South Australia
Stillbirth	A stillborn baby is at least 20 weeks gestation or, if it cannot be reliably established whether the period of gestation is more or less than 20 weeks, with a body mass of at least 400 grams at birth, that exhibits no sign of respiration or heartbeat, or other sign of life, after birth but does not include the product of a procedure for the termination of a pregnancy.
Viability	Ability to survive outside the womb

TERMINATION OF PREGNANCY

Legal Considerations

Criminal Law Consolidation Act 1935 – Section 82A (excerpt)¹

82A—Medical termination of pregnancy

(1) Notwithstanding anything contained in section 81 or 82, but subject to this section, a person shall not be guilty of an offence under either of those sections—

(a) if the pregnancy of a [woman](#) is terminated by a legally qualified [medical practitioner](#) in a case where he and one other legally qualified [medical practitioner](#) are of the opinion, formed in good faith after both have personally examined the [woman](#)—

(i) that the continuance of the pregnancy would involve greater risk to the life of the pregnant [woman](#), or greater risk of injury to the physical or mental health of the pregnant [woman](#), than if the pregnancy were terminated; or

(ii) that there is a substantial risk that, if the pregnancy were not terminated and the [child](#) were born to the pregnant [woman](#), the [child](#) would suffer from such physical or mental abnormalities as to be seriously handicapped,

and where the treatment for the termination of the pregnancy is carried out in a hospital, or a hospital of a class, declared by regulation to be a prescribed hospital, or a hospital of a prescribed class, for the purposes of this section; or

(b) if the pregnancy of a [woman](#) is terminated by a legally qualified [medical practitioner](#) in a case where he is of the opinion, formed in good faith, that the termination is immediately necessary to save the life, or to prevent grave injury to the physical or mental health, of the pregnant [woman](#).

(2) Subsection (1)(a) does not refer or apply to any [woman](#) who has not resided in South Australia for a period of at least two months before the termination of her pregnancy.

(3) In determining whether the continuance of a pregnancy would involve such risk of injury to the physical or mental health of a pregnant [woman](#) as is mentioned in subsection (1)(a)(i), account may be [taken](#) of the pregnant [woman](#)'s actual or reasonably foreseeable environment.

(5) Subject to subsection (6), no person is under a duty, whether by contract or by any statutory or other legal requirement, to participate in any treatment authorised by this section to which he has a conscientious objection, but in any legal proceedings the burden of proof of conscientious objection rests on the person claiming to rely on it.

(6) Nothing in subsection (5) affects any duty to participate in treatment which is necessary to save the life, or to prevent grave injury to the physical or mental health, of a pregnant [woman](#).

(7) The provisions of subsection (1) do not apply to, or in relation to, a person who, with intent to destroy the life of a [child](#) capable of being born alive, by any wilful act causes such a [child](#) to die before it has an existence independent of its mother where it is proved that the act which caused the death of the [child](#) was not done in good faith for the purpose only of preserving the life of the mother.

(8) For the purposes of subsection (7), evidence that a [woman](#) had at any material time been pregnant for a period of twenty-eight weeks or more shall be *prima facie* proof that she was at that time pregnant of a [child](#) capable of being born alive.

(9) For the purposes of sections 81 and 82, anything done with intent to procure the miscarriage of a [woman](#) is unlawfully done unless authorised by this section.

(10) In this section and in sections 81 and 82—
"woman" means any female person of any age.



Clinical and Ethical Practice Considerations

Staff have a legally protected right to refuse to be involved in termination of pregnancy, except when it is necessary to save the life, or to prevent grave injury to the physical or mental health of a pregnant woman¹.

The SA Maternal and Perinatal Mortality Committee³ recommend that,

“all clinicians involved with clinical care for perinatal deaths or mortality review should attend an ‘IMPROVE’ (Improving Perinatal Mortality Review and Outcomes via Education) workshop”.

Threshold of Viability

A child “capable of being born alive” for the purposes of section 82A(7) of the CLCA¹ is a viable child in the sense that, whilst it may require medical assistance, it has the capacity to live independently of its mother. It does not refer to the ability to show ‘signs of life’. This is always a clinical assessment that must be undertaken ‘in good faith’.

Gestation is not the only determinant of capacity to be born alive.

The prognosis for infants born extremely prematurely is affected by a number of factors. These include the infant’s gestation, birth weight, gender, whether a singleton or multiple birth, whether or not the mother has received antenatal corticosteroids or magnesium sulphate, and the presence of acute chorioamnionitis, fetal compromise or major congenital malformations.⁴ See *Perinatal Care at The Threshold of Viability* PPG to assist with the clinical determination of viability.

Late Stage Termination of Pregnancy in SA

Consistent with the CLCA¹ (excluding an emergency situation where a termination is necessary to preserve the life of the mother), it is recommended that each Local Health Network (LHN) has a local documented procedure and process (such as case conferencing), which will be implemented when a woman requests a later stage termination of pregnancy.

Timing of Screening, Diagnosis and Referral

Screening procedures and diagnostic tests to detect structural and fetal anomalies may be carried out in the first and second trimesters.

Perinatal care providers should be aware of the current requirements for termination of pregnancy in SA to ensure timely referral and assessment, thus enabling women the option of termination of pregnancy should they choose (Note: Flinders Medical Centre, Lyell McEwin Hospital and Women’s and Children’s Hospital will only commence TOP up to 22 weeks and 6 days gestation (22⁺⁶). TOP after this time can only be performed following agreement at case conferencing as per local policy.)

Specific testing for genetic disorders may be available in some clinical situations. Early consultation with a Clinical Geneticist for women at increased risk is essential, preferably prior to conception.

Consideration of factors that increase a woman’s risk for having a baby with chromosomal or structural anomalies should result in early specialist referral.

Perinatal care providers should be aware of current time periods for additional testing to ensure appropriate timing of initial and any subsequent screening and/or assessment.

Parental decisions about screening and diagnostic testing must be made on the basis of clear information about the nature and risks of the available interventions. Offer written information and time to consider choices.

For more information see relevant PPG available at www.sahealth.sa.gov.au/perinatal

Decision Making for Women

Prior to a decision for termination of pregnancy

In cases where the fetus has structural and/or other anomalies, the medical practitioner counselling the pregnant woman should explain:

- The full nature of the fetal abnormality
- The possibility that the abnormality will be lethal (if applicable)
- The probability of impaired cognitive function (as indicated)

- The known degree or likelihood of physical impairment
- Time constraints for TOP in SA

Counselling from a clinical geneticist, paediatrician or paediatric surgeon may be helpful in specific cases.

Parents faced with antenatally diagnosed fetal anomalies may need additional support whether they proceed with the pregnancy or decide to request a termination of pregnancy. Parents should be offered non-medical counselling at the time a diagnosis or suspected diagnosis is made (e.g. referral to a social worker or genetic counsellor).

Following a decision to proceed with termination of pregnancy

Pregnancies in the second trimester can be terminated medically or surgically depending on gestation, women's preference and other clinical considerations:

1. Medical TOP involves inducing labour with mifepristone and misoprostol (see *Termination of Pregnancy and Miscarriage in the Second Trimester* PPG⁵ available at www.sahealth.sa.gov.au/perinatal)
2. Surgical TOP involves a dilatation and evacuation procedure. Misoprostol, mifepristone, laminaria tents or a cervical balloon catheter may be used for cervical priming preoperatively. In SA, surgical TOP at later gestations may be an option in some circumstances following consultation with the care provider.

The medical officer counselling the pregnant woman should discuss the following to inform her choice:

- Whether the woman wishes to see and hold her baby and/or create mementos (see [mementos](#) section)
- Whether the experience of labour is important to her
- The time involved for different methods of termination
- The possibility that a surgical procedure may preclude viewing and handling of the fetus and may lead to some limitations with pathological examination
- The possibility that the fetus may show signs of life following a medical TOP
- In cases where it is anticipated that signs of life may be present at the time of birth, a discussion of the risks and benefits for the mother and fetus regarding the option of feticide, should take place. If the woman declines the option of feticide, she should be counselled regarding the possibility of the baby being born alive and the legal and legislative reporting implications of this (i.e. registration of live birth and subsequent death as per the *Births, Deaths and Marriages Act 1996*⁶)
- No resuscitation can be offered to a fetus undergoing TOP
- Any specific clinical circumstances (e.g. uterine scar) that may influence choice

In addition, the medical officer should discuss (and gain consent for) other possible investigations if indicated (e.g. amniocentesis, fetal tissue for chromosome analysis and/or DNA storage, histopathological investigation of the placenta) and [autopsy](#) (discussed in more detail later).

Documentation

Green C.O.R. 19 Form

The green C.O.R. 19 form 'CERTIFICATE TO BE COMPLETED WHEN AN ABORTION IS PERFORMED UNDER SECTION 82A OF THE CRIMINAL LAW CONSOLIDATION ACT 1935' must be completed before the procedure is performed.

When referring a woman to a health unit for a termination, the referring doctor should certify the green C.O.R. 19 form and send it to the health unit for certification by a second doctor before the termination. The original form must be delivered or posted in a sealed envelope marked *Confidential* to the Pregnancy Outcome Unit, South Australian Department for Health and Wellbeing within 28 days of the TOP. A copy of this form must be retained by the doctor who performed the TOP for a period of three (3) years commencing on the date of the termination.

Overt signs of life

If there are overt signs of life determined at the time of birth, regardless of gestation, an APGAR score is assigned. A time of birth and then a time of death must be recorded.

The birth is to be recorded in the hospital birth register.

Hospital notification of live birth to Births, Deaths and Marriages is required.

Individual LHNs must follow their local procedures and complete a 'Coroner's notification checklist' or equivalent check as per the *SA Health Coronial Process and the Coroners Act 2003 Policy Directive*⁷ for every birth with overt signs of life to exclude that the death is reportable to the Coroner.

ONLY in cases where the fetus exhibits overt signs of life at the time of birth (i.e. respiration or heartbeat or other sign of life), does the birth become registrable, rather than a product of a termination of pregnancy under the *Births, Deaths and Marriages Registration Act 1996*⁶. In these cases the hospital issues the following paperwork:

- A Birth Registration Statement
- A Perinatal Death Certificate
- Centrelink Bereavement Payment Form (for gestations \geq 20 weeks)

If no overt signs of life at birth, there is no requirement to assign an APGAR score or to register the birth regardless of the gestation.

Supplementary Birth Record Form and Confidential Report on Perinatal Death Form

All perinatal losses (including termination of pregnancy) over 20 weeks or over 400 grams require a 'Supplementary Birth Record' form to be completed under the *Health Care Regulations 2008*⁸ and a 'CONFIDENTIAL REPORT ON PERINATAL DEATH' form ('the blue form') to be sent to the Pregnancy Outcome Unit, SA Department for Health and Wellbeing.

Centrelink Bereavement Payment Form

Births, Deaths and Marriages is a registration body regulated under South Australia law and what constitutes a registrable birth in SA is not necessarily consistent with other Australian states or territories.

Centrelink acts on behalf of the Australian Government Family Assistance Office and is under the jurisdiction of the Commonwealth Government. The Commonwealth Government recognises all pregnancies over 20 weeks, including a stillborn child or pregnancy ended via termination of pregnancy. The woman should be issued with a Centrelink Bereavement Payment Form if the pregnancy reached 20 weeks gestation as women / families may be entitled to a bereavement payment under the Australian Government Family Assistance Scheme.

FETAL DEMISE

Fetal demise (whether early or late) requires confirmation from a formal ultrasound.

Fetal demise from 20 weeks gestation (Intrauterine Fetal Death/Stillbirth)

According to the *Births, Deaths and Marriages Registration Act 1996*⁶, a stillborn baby is at least 20 weeks gestation or, if it cannot be reliably established whether the period of gestation is more or less than 20 weeks, with a body mass of at least 400 grams at birth, that exhibits no sign of respiration or heartbeat, or other sign of life, after birth but does not include the product of a procedure for the termination of a pregnancy.

The birth of a stillborn baby should be registered.

A certificate of death is also required:

- Following a stillbirth, a doctor's certificate on the form approved by the Births Deaths and Marriages Registrar, certifying the cause of fetal death should be given to:
 - a) The Births Deaths and Marriages Registrar
 - b) The funeral director or other person who will be arranging for the disposal of the human remains (Note: A copy of the death certificate should also be given to the parents to give to the undertaker if they take their baby home and then to the funeral parlour)

- If an autopsy is undertaken, the death certificate is signed by the doctor carrying out the post-mortem
- If an autopsy is not undertaken, the death certificate should be signed by the doctor caring for the woman and her stillborn baby (any legally qualified practitioner can sign)

Fetal demise prior to 20 weeks gestation in singleton pregnancy

In a singleton pregnancy, if a baby is known to have demised prior to 20 weeks gestation but is born after 20 weeks gestation, this is considered to be a miscarriage (same rule applies as with multiple pregnancy). The date of baby's demise must be based on medical opinion, not on parent's wishes.

In these circumstances:

- Application for a Commemorative Certificate for Early Loss of Pregnancy is available to parents upon request.
- As the gestation is reliably known to be less than 20 weeks gestation, the mother is not eligible for a Bereavement payment

Spontaneous birth prior to 20 weeks gestation with overt signs of life

In the event that a fetus is born spontaneously with signs of respiration or heartbeat or other signs of life before 20 weeks gestation, this is classified as a birth and subsequent neonatal death and the following is required:

- A Birth Registration Statement
- A Perinatal Death Certificate
- Hospital notification to Births Deaths and Marriages

Multiple Pregnancy

Fetal demise of a multiple before 20 weeks gestation

If fetal demise of one multiple can be reliably known to have occurred before 20 weeks of gestation, but this fetus is not delivered until after 20 weeks of gestation, it is considered a missed miscarriage, and therefore is NOT eligible for Birth Registration or a Death Certificate. A Centrelink Bereavement Payment form is NOT issued for the demised fetus. Furthermore, the pregnancy will not continue to be regarded as a multiple pregnancy as only one fetus has reached viability and this fetus will become eligible for registration at the time of birth.

Fetal demise of a multiple after 20 weeks gestation

Each fetus, reliably known to be alive at 20 weeks gestation or more, born spontaneously, must be registered irrespective of its weight or whether live or stillborn at the time of birth.

A Birth Registration Statement must be issued.

Hospital notification to Births, Deaths and Marriages is required.

Either a Centrelink 'Newborn Child Declaration' form is issued OR, if stillborn the mother is eligible for a Bereavement payment and a Centrelink Bereavement Payment Form should be issued.

If subsequently, neonatal death of one or more of the babies occurs:

- A Perinatal Death Certificate must be issued
- A Bereavement payment form for the baby (or both) is issued as a replacement for the 'Newborn Child Declaration' form.

Fetal demise gestation uncertain

However, if gestation at death is uncertain and the weight of the dead twin is 400 grams or greater, the birth of that baby must be registered and the following must be issued:

- A Birth Registration Statement
- A Perinatal Death Certificate
- Centrelink Bereavement Payment Form

Hospital notification to Births, Deaths and Marriages is also required.

Medical or Surgical Management

Women experiencing fetal demise in the second trimester have the same options as women undergoing TOP depending on gestation, women's preference and other clinical considerations (see ['Following a decision to proceed with termination of pregnancy'](#) section).

Care of the woman experiencing perinatal loss⁹

Aim for continuity of caregivers.

Explanation and support for the woman and her family should begin immediately following confirmation of fetal death or decision for medical termination.

Parents should be offered non-medical counselling at the time that a diagnosis or suspected diagnosis is made e.g. referral to a social worker or genetic counsellor.

The emotional and psychological preparation related to the timing of the induction / termination procedure after diagnosis should be discussed with the woman.

Discuss the woman and her family's option to see, touch and hold the baby after birth, receive [mementos](#) (discussed below), and take photographs. Parents may be unsure about seeing and holding their baby after death. It is important that staff gently explore any parental concerns and respects their choice to do what is right for them.

Offer stillbirth and neonatal death support group information (such as SANDS) and brochures to the woman and her family.

In the case of a termination of pregnancy for a fetal abnormality offer information about the Support After Fetal Diagnosis of Abnormality (SAFDA) support group.

Obtain intravenous access and take bloods as indicated (see *Investigation of Stillbirths: SA Protocol*¹⁰ available at www.sahealth.sa.gov.au/perinatal)

- Group and save
- Complete blood picture
- Coagulation profile (if at risk of coagulopathy or > 24 hours after IUFD)

Arrange early anaesthetic review. If regional block required, obtain results from complete blood picture and coagulation profile before insertion.

Culturally sensitive care

Women often have different values, perceptions and behaviours that differ not only across cultural backgrounds but also within their own culture⁹.

Health professionals should ask women if there are specific cultural practices that they need to observe/be aware of (rather than assume), in order to provide culturally appropriate care.

It is important for health professionals to acquire a general working knowledge of those practices that may be considered offensive in some cultures.

Health professionals should be aware that families from other cultural backgrounds may have very different belief systems and practices around death and important rituals that need to be performed.

A detailed account of various multicultural practices around death is beyond the scope of this guideline. A brief description of issues that may be relevant for Aboriginal and Muslim women is included:



Aboriginal women

Aboriginal people experience very high levels of grief and loss in their communities. This can demand ceremonial acknowledgement. Aboriginal women should be referred to an Aboriginal Health Professional as soon as practicable

It may be important for Aboriginal women to include their extended family who may or may not include blood relatives when grieving perinatal loss.

Utilise Aboriginal liaison services where available as support until the arrival of relatives.

It is important to understand that eye contact and questioning may be offensive to the woman.

Ensure the woman is aware of any Aboriginal services as well other available services (including funeral options) so that choices most appropriate to the woman's cultural needs can be made.

Muslim women

According to Islam, for forty days following birth, the mother of a stillborn baby is unclean and may not touch a dead body.

The stillborn baby may be washed by a relative of the same sex.

Early discharge may be requested for early burial of the stillborn baby.

The stillborn baby should be interred (usually in a shroud) within 24 hours after death (may be without a coffin). The funeral service is usually held in a Mosque, but may also take place in a funeral parlour or cemetery. The family usually make their own burial arrangements for the baby with the funeral director. Cremation is not usual.

These arrangements may affect the hospital's ability to create mementos.

If required, autopsy should be expedited for the parents.

Care of the woman following birth

It is important that the wishes of the woman and her family in relation to seeing, touching and holding their baby are respected at this time⁹.

If appropriate, the parents should be encouraged to name their baby and begin to develop memories of their baby. As appropriate, parents may include siblings and other family members in photographs to aid the development of memories following their baby's death.

Observations as indicated and allow parents some time alone as appropriate

If the placenta is retained, arrangements should be made for evacuation of the uterus in theatre. The urgency of performing this procedure should be determined by the amount of ongoing vaginal blood loss.

Lactation suppression

Provide the opportunity for open and sensitive discussions regarding options for lactation suppression.

Prolactin is the primary hormone responsible for milk production, and in its absence, milk production ceases. Prolactin levels attain their highest levels in the third trimester and continue to increase until term. Advise that breast milk production may take some time to resolve, and can range from a few days to weeks¹¹.

Many women may find that production of milk is a reminder of the loss of their baby and will wish to initiate early suppression of lactation; however others may find that it produces positive emotions during a sad time and may wish to employ gradual suppression of lactation¹² (particularly if perinatal loss has occurred after lactation has been established).

Measures to alleviate uncomfortably full breasts include¹¹:

- encourage the woman to wear a firm bra or crop top day and night until breasts feel less full and avoid expressing or overstimulating her breasts
- simple analgesia such as paracetamol
- use of cold packs
- gentle massage of breasts under the shower to alleviate discomfort and allow some milk to leak
- the use of breast pads to soak up any leaking milk

For further information see Australian Breastfeeding Association information 'Lactation after infant death' at URL: <https://www.breastfeeding.asn.au/bfinfo/lactation-after-infant-death>

Cabergoline (Dostinex®)

Pharmacological suppression may be offered and is suitable from 20 weeks of gestation or may be considered earlier if lactation suppression is thought to be required¹².

Cabergoline (Dostinex®) is most effective if given as a single oral dose of 1 mg in the first 24 hours postpartum¹³.

An ergot derivative, cabergoline (Dostinex®) should be given with caution in women with a history of severe cardiovascular disease, hypertension, preeclampsia and women with a history of serious psychiatric disorder (particularly psychosis)¹³.

Common side effects include dizziness, nausea, headache and hypotension¹³.

Care of the baby following birth

The gender of the baby should not be identified if any doubt exists. Indeterminate sex should be documented in the notes and pathological examination to determine gender should be requested as soon as possible. The gender can be determined within 24 hours by the South Australian Perinatal Autopsy Service at the Women's and Children's Hospital (WCH).

If parents wish to see and hold their baby, ensure baby is wrapped and presented in a way that is sensitive to their individual needs.

There should be someone close at hand to remove the baby when appropriate.

Document weight and length, date and time of birth, gender and name of baby in case notes and on memento card for parents.

Medical / midwifery staff should be aware and advise women and their family as appropriate, that refrigeration (at 4° Celsius) of the baby is advised at least within the first 24 hours. If the woman wishes to keep her baby with her, staff should encourage regular periods of refrigeration (e.g. overnight if possible). Alternatively, offer use of portable devices (e.g. a 'cold-cot') to facilitate the woman's access to her baby if available.

Blessing baby

Women and their family may choose to have a blessing of their baby (may be arranged privately or midwifery staff can notify the hospital chaplain or other appropriate denomination if available).

Discharge planning

Contraception advice as appropriate.

Lactation suppression advice as above.

Ensure the woman is aware of the signs and symptoms of mastitis (e.g. flu-like symptoms with aches, fever, breast lumps, red, swollen, hot and painful area of the breast, red streaks extending toward the axilla¹² and advise the woman to seek medical advice if symptomatic.

Offer the woman follow-up counselling by the service provider or another appropriate agency / counsellor.

Arrange domiciliary follow up as indicated.

Medical discharge letter.

Follow up medical appointment according to individual hospital arrangements. At this appointment the woman should undergo a physical review and receive the results of any investigations / autopsy in a plain language report (may take 8-10 weeks to complete). A formal report is sent to the referring general practitioner.

Where possible, if the woman has transferred from the country and the woman's general practitioner (GP) is unaware of the pregnancy outcome, the GP should be notified by telephone (with the woman's consent).



Mementos

Mementos can be created by individual health units and/or the SA Perinatal Autopsy Service.

All babies who have post mortem examination by the SA Perinatal Autopsy Service will have the option of a memento package including:

- High quality colour digital photographs
- Foot and hand prints
- Name band
- Hair (if possible)

Mementos created by the SA Perinatal Autopsy Service will only be undertaken if the *Memento Package Request Form* is completed and received (see [appendix](#)).

Parents who do not wish to receive these mementos at first may still choose to have them undertaken as they may change their minds at a later date (several weeks, months or years after their baby's death), and wish to collect their baby's items. Storage of mementos as part of the SA Perinatal Autopsy Service is consistent with the SA Health *Health Record Management Policy Directive 2017*¹⁴.

Destruction of mementos, as part of the health record, should only occur once they have reached their legal period of retention in accordance with the *State Records General Disposal Schedule No. 28 - Clinical and Client Related Records*¹⁵ (currently 33 years).

Women should be informed that if mementos are not collected after 33 years they will be destroyed. The discussion should be clearly documented in the woman's medical record.

Individual hospitals may also create memento packages for second trimester fetal loss, stillbirths and neonatal deaths. Mementos may include some or all of the following: identification bracelets, cot cards, tape measures used to measure baby (as appropriate), naming certificate, memento box and clothing (e.g. gown, bonnet, quilt).

Individual LHNs/health units need their own processes for management of mementos which may include indefinite storage, but at a minimum this should be 33 years, consistent with the *State Records Disposal Schedule*¹⁵.

Placenta

Histological examination of the placenta may provide additional clinical information⁹.

Where possible, all placentas of stillborn infants, early neonatal deaths and mid-trimester miscarriages / genetic terminations should be sent for examination³.

The placenta should also be sent to histopathology if a chromosomal abnormality is suspected or neonatal fetal death is probable.

Twin placentas must be adequately labelled as Twin I and Twin II.

Document description and weight of placenta in case notes.

The placenta should be sent as soon as possible (i.e. within 12 hours) fresh, without any preservative solutions or refrigerated if there is any delay. See *Histopathology Management of the Placenta* PPG¹⁶ available at www.sahealth.sa.gov.au/perinatal

If consent for Autopsy

The placenta is sent with the fetus to the South Australian Perinatal Autopsy Service at the Women's and Children's Hospital (WCH mortuary).

If no autopsy

The placenta should be sent to the hospital's histopathology department with consent.

Autopsy

Consent to autopsy is legally required for any fetus over 20 weeks, weighing over 400 grams or where there are overt signs of life at lesser gestations necessitating issue of a birth and then a death certificate. However, the South Australian Perinatal Autopsy Service requires that consent to autopsy or pathological examination at any gestation is obtained (see *SA Transplantation and Anatomy Act 1983*¹⁷), to ensure there is no misunderstanding and the wishes of the woman and partner are respected.

The South Australian Perinatal Autopsy Service (at the Adelaide Women's and Children's Hospital) provides a perinatal autopsy service for all public and private hospitals in South Australia, as well as Alice Springs Hospital, Broken Hill and Mildura.

A plain language autopsy report can be requested from the South Australian Perinatal Autopsy Service (phone: 8161 6315) at any time. If it is anticipated that a plain language autopsy report will be required, this may be requested on the original autopsy consent form at the time of autopsy consent.

Coronial enquiry – stillborn babies do not require investigation by the Coroner. Investigation is at the Coroner's discretion.

Purpose of perinatal autopsy

The SA Maternal and Perinatal Mortality Committee³ strongly recommend autopsy and histopathological examination of the placenta in cases of stillbirth in addition to following the *Investigation of Stillbirths: SA Protocol*¹⁰ (available at www.sahealth.sa.gov.au/perinatal).

PSANZ lists the following reasons for performing an autopsy⁹:

- Identify an accurate cause of death
- Exclude some potential causes of death
- Identify disorders that have implications for counselling and monitoring in future pregnancies
- Provide other information related to the death, including excluding possibilities that may alleviate feelings of guilt
- Obtain tissues for genetic tests
- Assist grieving by helping parents' understanding of the events surrounding the death
- Contribute to research, for example, by the recognition of new disease entities and expansion of knowledge on known diseases
- Inform clinical audit of perinatal deaths, including deaths due to iatrogenic conditions and to confirm antenatal diagnoses or suspected fetal pathology
- Teach pathologists and medical students
- Avoid inaccuracies in data on causes of death for audit activities and subsequent public health policy
- Inform medico-legal processes, for example, provide information in coronial investigations or cases of litigation

Consent for autopsy with the SA Perinatal Autopsy Service

The booklet, *When a person dies: The Hospital Autopsy Process. Information for family and friends*¹⁸ should be given to the parents to read before any request for autopsy consent from the medical officer.

It is the responsibility of the medical officer to answer any queries that the woman and her partner may have related to autopsy before obtaining their consent for autopsy⁹.

Parents can choose not to have an autopsy performed.

A copy of the autopsy report may be sent to the woman's general practitioner according to the woman's wishes (documented on form (b) MR82F).

Initial information from autopsy is generally available within six (6) to eight (8) weeks.



Forms

The following forms require completion and must be sent to the South Australian Perinatal Autopsy Service with the fetus / baby for autopsy.

- SA Health Authority for Post Mortem Examination: Part A – Request by Medical Practitioner form should be completed by the requesting doctor
- SA Health Authority for Post Mortem Examination: Part B – Record of Consent form should be completed by the senior available next of kin and signed by a witness (+/- interpreter if required). N.B. The witness must be independent (i.e. not the requesting doctor nor related to the deceased)
- SA Pathology Burial Authority Consent form (includes information required by Undertaker) OR
SA Pathology Disposal Arrangements Consent form (for stillbirths < 20 weeks or GTOPT ≥ 20 weeks with no signs of life)
- Memento Package Request form (see [appendix](#)) if the parents want the SA Perinatal Autopsy Service to create mementos.

The Confidential Report on Perinatal Death may be sent directly to the Pregnancy Outcome Unit as indicated on the form.

Transport of the fetus / baby for autopsy

The doctor at the transferring hospital should telephone (08) 8161 6101 to inform staff at the SA Perinatal Autopsy Service to expect a baby.

The referring hospital should arrange transport of the baby with SA Pathology on phone number (08) 8222 3000 or via Funeral director of choice.

Transport may be by road or air as appropriate.

The baby should be refrigerated at 4° Celsius until transfer.

For any fetus / baby being transported to the South Australian Perinatal Autopsy Service:

- The baby / bucket (not the lid) should be clearly labelled
- The baby should be wrapped in a shroud (sheet), then plastic
- A small fetus < 20 weeks may be transported dry in a bucket
- Transport without fixative or other fluids
- Include fresh placenta in sealed labelled bag
- Use a plastic esky with ice bricks (e.g. small containers of frozen water) carefully positioned around but separate from baby (or bucket) for cold storage transport
- It is important that baby is transported dry and undistorted
- Include demographic and clinical information including obstetric history of the mother

Note: A summary information booklet on the South Australian Perinatal Autopsy Service is available by contacting Anatomical Pathology at the WCH on phone number 8161 6315.

Burial or cremation options

Discuss burial, cremation or disposal options after birth as appropriate for gestation.

Organise social work support in accordance with individual hospital or medical arrangements.

Parents' grieving process is often assisted by involvement in a physical parting, thus a funeral (burial or cremation) may be an option at any gestation. The mortuary provides required paperwork.

Less than 20 weeks gestation (TOP or Miscarriage)

It is not compulsory for a funeral (burial or cremation) if a birth is not registered. Options therefore include:

- The woman organises a private funeral/disposal, and is responsible for all costs. The hospital mortuary or doctor/midwife can provide an *Early Loss of Pregnancy Letter* for the funeral director so a burial or cremation can occur (see <https://www.sa.gov.au/topics/family-and-community/births-deaths-and-marriages/certificates/early-loss-of-pregnancy-certificates> for link to letter template) OR

- The hospital arranges anonymous cremation through funeral consultants as per individual LHN arrangements (Note: The cremation may be with other fetus' and is not available at all hospitals) OR
- Disposal of the fetus as medical / clinical waste. Note: If an autopsy is being undertaken, the completed *SA Pathology Disposal Arrangements Consent* form will need to be sent with the fetus to the SA Perinatal Autopsy Service. If there is no autopsy, consent for disposal of the fetus will need to be documented as per local LHN process which may include use of the *SA Pathology Disposal Arrangements Consent* form.

IUFD or neonatal death from 20 weeks gestation

All intrauterine fetal deaths or neonatal deaths ≥ 20 weeks receive a birth certificate and a death certificate (excluding those babies that are a result of a termination of pregnancy unless liveborn). Funeral (burial or cremation) arrangements are made privately and the woman is responsible for all costs.

The above funeral requirements apply to all babies who die in the perinatal period (i.e. from birth to 28 days after birth) as well as second (≥ 20 weeks gestation) and third trimester fetal losses.

Termination of pregnancy from 20 weeks gestation

If no overt signs of life at birth and therefore not a registrable birth

Options are the same as for [Less than 20 weeks gestation \(TOP or Miscarriage\)](#), however, the hospital mortuary will need to provide a perinatal death certificate for the funeral director so a burial or cremation can occur if the woman chooses a private funeral.

If a live birth

Options are the same as for [IUFD or neonatal death from 20 weeks gestation](#).

Taking baby home

Greater than 20 weeks gestation

Usually, the undertaker from the chosen funeral parlour will collect baby from the hospital before burial, however, this is not a legal requirement.

Occasionally women may wish to take their baby home in preparation for the ceremony or before transporting baby to the funeral parlour.

Arrangements for the above should be made on a case by case basis.

Parents who take their baby home and then to the funeral parlour should also take a copy of the death certificate to hand to the undertaker with the baby. The original certificate should be forwarded to Births, Deaths and Marriages by the hospital.

In the above circumstances, it is important to explain to the parents:

- Cold storage requirements for the transport and care of their baby. Consider use of a 'cold-cot' if available
- It is their responsibility to take the baby to the funeral parlour within 24 hours

It is advisable for staff caring for the woman to obtain contact details of the receiving funeral parlour and telephone the funeral parlour the following day to ensure they have received the baby.

The baby may be dressed, dry wrapped and transported home in an esky (may be foam if no plastic esky available) with ice bricks (e.g. small containers of frozen water) carefully positioned around but separate from baby for cold storage transport.

Less than 20 weeks gestation / Termination of pregnancy

A fetus at less than 20 weeks gestation or a product of termination of pregnancy (without signs of life at birth) is not registrable and therefore not considered to be human remains. The fetus therefore cannot be interred in a cemetery unless an Early Loss of Pregnancy Letter (for gestations < 20 weeks) has been completed.

On request, in cases where there are no infection contraindications, women may take the remains of their baby home for burial.

In these circumstances, it is preferred that staff offer the available cremation service whereupon the ashes may then be taken home to be kept / scattered as appropriate.

If cremation has not been undertaken, the fetus should be wrapped in a waterproof shroud for transport and placed in a sealed ice box (e.g. esky containing ice bricks carefully positioned around but separate from the fetus) for cold storage.

The parents should be advised to contact their local council to ensure that burial is carried out in accordance with their local council regulations. Note: Whilst the Births, Deaths and Marriages Registration Act⁶ define human remains as at least 20 weeks gestation, local government Acts may consider a fetus of any gestation to be human remains. This will affect individual burial options.



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Useful Websites

PSANZ and Stillbirth Centre of Research Excellence

Clinical Practice Guideline: Care around Stillbirth and Neonatal Death

<https://www.stillbirthcre.org.au/resources/clinical-practice-guidelines/>

PSANZ Stillbirth and Neonatal Death Alliance

<https://sanda.psanz.com.au/>

SANDS

<https://www.sands.org.au/>

South Australian Perinatal Autopsy Service

<http://www.wch.sa.gov.au/services/az/divisions/labs/sapas/index.html>

Support after Fetal Diagnosis of Abnormality (SAFDA)

<http://www.wch.sa.gov.au/services/az/divisions/labs/geneticmed/safda.html>

SA Health website information on abortions

<https://www.sahealth.sa.gov.au/wps/wcm/connect/public%20content/sa%20health%20internet/health%20topics/health%20conditions%20prevention%20and%20treatment/abortions/abortions>



Appendix: SA Perinatal Autopsy Service Memento Request Form

MEMENTO PACKAGE REQUEST

AFIX PATIENT LABEL HERE

If requested by families, the laboratory staff at the Women's and Children's Hospital are willing to prepare Mementos. This can include any of the items listed below where possible.

It is important to note that if 'NO' is selected, a memento package will **not** be created and cannot be provided at a later time.

On completion, the package will be distributed via Women's Social Work at the Women's and Children's Hospital and where relevant the originating hospital.

A Memento Pack is requested for _____ (Baby's name)

YES NO

If "YES" Which of the following items are requested to be included?

1. Photographs YES NO
 These can be taken with the baby:
 a) Dressed or wrapped YES NO
 b) Not dressed YES NO

Any additional requests _____

2. Hand and foot prints YES NO
 3. Lock of hair (where possible) YES NO
 4. Hospital ID bracelet YES NO
 5. Hospital bed card (WCH only) YES NO

Any additional requests _____

Name _____ Mother/Father

Signature _____ Date ____ / ____ / ____

Phone consent taken by:

Name _____

Signature _____ Date ____ / ____ / ____



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